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Editorial

Fear of recurrence

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This issue of the *Journal of Neurosurgery* contains an interesting article by Covey and colleagues on the important issue of the fear of recurrent subarachnoid hemorrhage (SAH) in patients and their significant other (SO), who was usually the spouse but could be another family member or close friend most intimately identified with the patient.[1] Essentially, the authors attempted to quantify by neuropsychological testing the magnitude of that fear and its effect on the general well-being of the patient and his/her SO. Not surprisingly, they found that the fear factor was of substantial magnitude and that it significantly impacted the quality of life of the patient. Surprisingly, however, they found that this fear of recurrence was actually greater in the SO than in the patient and that fear on the part of the SO had a very significant effect on the quality of life of the patient, presumably by excessive "nurturing" and imposition on the patient by his/her SO of restrictions on things such as return to work, physical activity, driving, sexual intercourse, and so on. Interestingly, the authors found that the fear of recurrent SAH in these patients and their SO was greater than the fear of the patient developing Parkinson disease, lung cancer, or a heart attack. Perhaps this can be explained by the fact that the fear of a recurrence of something that the patient has already experienced far outweighs the impact of the fear of other equally serious but hypothetical problems that the patient has not experienced personally.

Like most studies, this one has some weaknesses that the authors have done a good job in discussing. First of all, it should be noted that none of the 3 authors is a neurosurgeon, and therefore the study has a strict psychological perspective. Additionally, the number of patients (69) is small and this is a highly selected population of patients who were obviously in good neurological condition at the time that the psychological evaluation was applied (approximately 13 months after the ictus) and, as expected, the great majority of them (71%) were World Federation of Neurosurgical Societies Grade I at the time of their SAH. An additional bias is that the study was conducted through permission by the patient, who then allowed his/her SO to be contacted for the test; this may have selected a particular group of patients in whom the issue of fear of recurrence by the SO and its impact on the patient may have been more important.

Needless to say, I cannot comment with any degree of expertise on the validity of the neuropsychological tests administered or the statistical interpretation of the results. Therefore, I will confine my comments to the role of the neurosurgeon in promoting or mitigating the fear of recurrent SAH in our patients and their SOs. My comments will by necessity be highly subjective and derived from personal experience much more than from scientific data, which is very scarce on this topic. Additionally, I do not think that it is necessary to discuss the patients who have had an aneurysmal SAH and in whom the aneurysm has either not been treated or has been incompletely coiled or incompletely clipped. It is obvious that these patients need to be followed up very carefully in a routine manner, and there are fairly good guidelines about this. Likewise, enough data have now been gathered to know that there is a significant rate of recurrence of aneurysms that have been initially completely coiled, and again there are good guidelines on how these patients should be followed up. The issue I want to discuss is the one with which I have had the most experience; the patient who has had an SAH from a single aneurysm that has been satisfactorily clipped at surgery, with complete occlusion being confirmed either by intraoperative observation or, preferably, by angiography done during surgery or postoperatively.

I will begin my discussion by briefly supporting the widely held notion that the risk of a recurrent SAH from a satisfactorily clipped aneurysm or of developing a de novo aneurysm that could potentially result in an SAH is very, very small. David et al.[2] reported on a consecutive group of 102 patients with 167 aneurysms in whom a late angiogram was obtained at a mean of 4.4 years after clipping of a ruptured aneurysm by an expert neurosurgeon. Only 1 of these patients had a recurrent SAH during the follow-up period, which resulted in a calculated yearly rate of rebleeding of 0.26%. There were only 2 aneurysms that recurred from the group of patients who had complete clipping of the aneurysm confirmed by intraoperative or

early postoperative angiography. There were 8 de novo aneurysms found on late angiographic studies, but 7 of these developed in patients who had multiple aneurysms, and there was only 1 de novo aneurysm in patients who had a single aneurysm satisfactorily clipped. In the International Subarachnoid Aneurysm Trial, over a 4-year period of follow-up there were only 2 rehemorrhages in the group of 1055 patients who had their ruptured aneurysm clipped.[3]

Wermer et al.[5] reported 18 recurrent SAHs out of a group of 752 patients with a total of 6016 years of follow-up (mean follow-up 8 years). Of these 18 recurrent rehemorrhages, only 4 were found to be from the aneurysm that had bled previously and was clipped, which results in a 0.53% incidence of recurrent SAH from the clipped aneurysm. In this series, however, complete clipping of the aneurysm was not confirmed by intraoperative or immediate postoperative angiography. This study also confirmed that the presence of multiple aneurysms was a very significant risk factor for recurrent SAH. Finally, Tsutsumi and colleagues[4] found a cumulative risk of recurrent hemorrhage of 2.2% over a 10-year follow-up period in 220 patients with a clipped aneurysm, and only 2 patients (0.9%) had regrowth of the originally clipped aneurysm at follow-up angiography.

Accepting the fact that the risk of recurrent SAH from a satisfactorily clipped aneurysm or of developing a new aneurysm is extremely small, how should the treating neurosurgeon counsel the patient and his/her SO after recovery from an aneurysmal SAH and satisfactory clipping of a single aneurysm that was responsible for the SAH? At one extreme would be to advise the patient that "You are cured and you don't have to worry any more about an aneurysm. You don't need to see me on a routine basis unless there is a problem, but I don't expect any problems." Or at the other extreme, "You know even though this aneurysm was taken care of for now, it could recur in the future and you could have another SAH or you may develop a new aneurysm, so we need to follow you very closely and repeat the angiogram periodically to make sure that this aneurysm remains occluded and that you don't develop any other aneurysms, which is something that is more likely to happen after you already have had a ruptured aneurysm."

I don't think there should be any question about the fact that speaking to the patient and the SO in the former manner could have a significant effect in alleviating a fear of recurrence, whereas that fear could be very significantly exacerbated by the second statement. Perhaps most of us would agree that the best way to advise the patient falls in between these two extreme approaches. As in everything else we do, it is hard not to have to contend, unpleasant as this is to all of us, with medicolegal implications. Clearly, the physician making the second statement, particularly if it is well documented in the patient's record, may feel well "protected" from the medicolegal point of view if the patient does indeed suffer a recurrent SAH or develops a new aneurysm in the future. The physician making the first statement about the patient being cured and not having to worry any more about another SAH or aneurysm may feel more vulnerable from this point of view. Therefore, each one of us would have to make an ethical but practical decision about the relative weight of the extremely small probability of being sued because of a recurrence in the future and the possible impact of our advice to the patient and his/her SO on the patient's future mental health and well-being.

Before continuing, I would like to digress with a personal experience that stimulated my interest in this issue early in my career. Having moved to a new institution where I was to specialize in cerebrovascular surgery, I was instructed that one of my duties was to attend the monthly "aneurysm clinic." I went to the first of these clinics very excited, thinking that I would see new patients with unruptured aneurysms who were coming for evaluation and possible treatment. Not so. Every patient I saw had had his/her aneurysm already treated, and in most cases the treatment had been complete and satisfactory, and had taken place years (sometimes several years) before the clinic visit. It became evident to me during that initial clinic that almost all of these patients now had an "aneurysm disease" and that they believed that they had a chronic illness, and many of them dreaded this checkup visit for fear that "the aneurysm had come back." Furthermore, I found it difficult to "cure" some of these patients from their aneurysm disease by telling them that they had an extremely small chance of a recurrent SAH or a new aneurysm and that they did not need any further follow-up unless they had a problem. It seemed to me that after they had the "disease" for a few years, they couldn't trust me to offer them an instantaneous "cure." Needless to say, in a few months I was able to close down this "aneurysm clinic" and started to counsel patients individually after clipping the aneurysm, advising follow-up to some and not to others depending on many factors such as age, multiplicity of aneurysms, known residual neck, presence or absence of family history, psychological makeup of the patient, and so on.

As in so many "gray areas" in our specialty, I do not believe that we can or should develop guidelines on how each neurosurgeon should approach his or her patient after satisfactory treatment of a ruptured aneurysm. The best advice, as in most instances, is to be a complete physician and consider not just the scientific facts (extremely small chance of recurrence) but also the softer issue of psychological impact on the patient and his/her family, and to reach an individual decision tailored to each particular situation. In other words, to use the "art" of medicine as well as its science. To this effect, many factors need to be considered. Obviously, the younger the patient is, the more years that the individual would be at risk of developing a recurrence and the more inclined one would be to recommend some sort of follow-up. Conversely, what is there to be gained by recommending a periodic repeat imaging study in the future to a 71-year-old patient who has recovered satisfactorily from his/her SAH? Yes, there is a small chance that a recurrence or a new aneurysm may be detected in the future, but then, particularly when considering that the patient would be older at that time, one has to factor in the risk of treating that recurrence, which may well be a more difficult problem to treat in an older patient.

Presence of multiple aneurysms is clearly, as discussed before, an important risk factor for recurrent SAH or development of a de novo aneurysm even if all the aneurysms are treated, and periodic imaging follow-up is desirable in these patients. Family history of aneurysms is important and one would obviously be more likely to recommend more careful follow-up in patients with a significant family history of aneurysms, since it is clear that in those cases the chances of developing a de novo aneurysm are greater. The same goes, of course, for patients with diseases that predispose them to the formation and/or rupture of aneurysms, such as polycystic kidney disease, some of the collagen vascular diseases, and so on. Not to be neglected, of course, is the psychological makeup of the patient and his/her family. All of us should be able to evaluate this after dealing with them through the patient's illness and convalescence. We should be able to tell who would be relatively unaffected by the idea of needing follow-up just in case of the remote chance of a recurrence and, alternatively, who could be devastated by our emphasizing that such a chance exists.

Of course it is extremely important not only what specific advice to give in terms of follow-up, but how that advice is given. For example, if we believe that the risk of a recurrence justifies routine imaging in, say, 2 years after satisfactory treatment of a ruptured aneurysm, the impact may be very different if we say "You know, the chances of your having this problem ever again are extraordinarily small, but I think that just to be conservative and to reassure you, we should get another study in 2 years," as opposed to "You know, once you've had an SAH, you really need to be followed up very carefully because the aneurysm, even though we clipped it satisfactorily, could recur, and certainly you have a much greater risk than someone who has never had an aneurysm of developing another one, so we must do an angiogram no longer than 2 years from now."

In conclusion, my opinion is that the available data indicate that the frequency of a recurrent SAH, regrowth of the clipped aneurysm, or formation of a de novo aneurysm in a patient who has had a ruptured aneurysm satisfactorily clipped is extremely small, and therefore the neurosurgeon is justified in being very reassuring to such a patient and his/her family and is under no imperative to recommend routine follow-up or imaging studies to all these patients. Whether to do so or not should be an individualized decision based on a number of factors, of which one of the most important is the possible psychological impact on the patient and the family. Of course, patients in whom the aneurysm was incompletely clipped or coiled, patients with multiple aneurysms, a family history of aneurysms, or a disease predisposing to the formation and rupture of aneurysms should have periodic follow-up, but the frequency of such and the way in which the patient is counseled, once again, requires individual consideration of a multiplicity of factors including psychological ones.

We are grateful to Dr. Covey and her colleagues for emphasizing the impact of fear of recurrence in patients with SAH and in their spouse or closest relative or friend.
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Disclosure

The author reports no conflict of interest.

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Response

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In his editorial on our article published in this issue of the *Journal of Neurosurgery*, Dr. Heros comments on the role of the neurosurgeon in promoting or mitigating the fear of recurrent SAH in patients and their SOs. He supports the widely held notion that the risk of a recurrent SAH from a satisfactorily clipped aneurysm is very small, and raises the question about how the treating neurosurgeon should counsel the patient and his/her SO.

Drawing on his own personal experience, he highlights the limitations of simply reassuring patients that they had an extremely small chance of a recurrent SAH and that they did not need any further follow-up. The limitations of reassurance seemed particularly notable in patients who had been visiting the aneurysm clinics for checkups for several years since their aneurysm had been treated. The idea of needing a follow-up and checkup may in itself propagate the perception that there must be a noteworthy chance of recurrence, and Dr. Heros concludes his editorial by presenting the opinion that recommending routine follow-ups or imaging studies to all patients could be ill-advised. The approach to reassurance adopted, including the decision whether to offer routine follow-up, should be individually tailored and based on a number of factors, including the neurosurgeon's evaluation of the psychological make-up of the patient and the family.

We think that the recommendations provided by Dr. Heros have the potential to reduce the problem significantly. That being said, we would like to draw the readers' attention to the fact that counseling and information provided by the neurosurgeon, while being an important factor, is not the only relevant factor that determines the fears of patients and their SOs.

One potentially important factor for neurosurgeons to consider and identify is posttraumatic stress disorder (PTSD), which we have found is strongly associated with whether patients experience the debilitating and disproportionate fear of SAH recurrence that Dr. Heros describes.[7] Studies have shown that the prevalence of PTSD, which is characterized by intrusive recollections of the trauma and active avoidance of stimuli associated with it, can be at least 3 times times more prevalent in patients with SAH[8] and their SOs[9] than it is in the general population. Our own research has also found that the development of PTSD in patients with SAH appears to be related to the stress of postictal events, including realizing all of a sudden that they could have died.[1]

It could therefore be argued that in PTSD the focus on the near miss of averting death has evoked a stress-inducing fear response that inflates perceptions of recurrence ("It could so easily have gone the other way—I might not be so lucky next time") rather than a relief response ("I'm thankful I'm still alive").[10] Of course, as shown in our article published in this issue of the *Journal of Neurosurgery*, the patients and their SOs may not share the same fears, and the reason for this may lie in the way that they have interpreted the future implications of the near-death incident. In light of the finding that SOs were more fearful of SAH recurrence than the patients, it is possible that SOs may be even more inclined than the patients themselves to interpret the near miss as a signal that their loved one "almost died" and "might not be so lucky next time."

Understanding and identifying how patients with SAH and their SOs have interpreted the near miss might therefore provide neurosurgeons and other health professionals with some valuable insights into the psychological impact that the traumatic event has had on them, and help target those individuals who may need more than standard reassurance or advice. In line with this, we previously reported how SAH patients with PTSD who were fearful of SAH were significantly less likely to see value in being provided with information about the true risk, in being reassured by their neurosurgeon, or in having repeated angiograms.[7] Why was that? We suggest that this is because a proportion of their fear is attributable to abnormal risk perceptions that result from PTSD—it does not, as treatment with information would suggest, merely represent a lack of understanding or need for reassurance. This argument is also supported by past research, which suggests that in patients who suffer from PTSD, information and advice alone are insufficient to alleviate their fears—as illustrated by the following quote from a qualitative study on patients with SAH conducted by Jarvis:[4] "I felt very very [sic] frightened about it happening again … even though I knew the facts about the chance of recurrence."

Unfortunately, many affected SAH patients do not seem to recover spontaneously from PTSD without psychological treatment. In a prospective study we found that the PTSD rates in patients with SAH were comparable at 3 and 13 months postictus, with most patients having the same PTSD status.[8] Specific psychological treatments such as cognitive-behavioral therapy and eye-movement desensitization and reprocessing have, however, been found to be successful for PTSDs that develop after the experience of other traumas such as motor vehicle accidents and assault.[3,5,6] However, although such psychological treatment is available and proven to be effective, its potential for reducing PTSD and its accompanying fears in patients with SAH and their SOs has not yet been evaluated. Whether fear in patients with SAH will be reduced if PTSD is effectively treated is unknown, and in our view such an evaluation should be an important research priority.

Identifying patients and their SOs who are at risk of PTSD and are demonstrating an abnormal fear response is also important. As a starting point we might therefore want to know whether neurosurgeons and other health professionals are able to identify the signs and symptoms in the course of their dealings with the patient and family through their treatment and convalescence. To this end we have, with the help of the support groups *Behind the Gray* (www.behindthegray.net), *The Brain & Spine Foundation* (www.brainandspine.org.uk), and *Headway* (www.headway.org.uk), recently finished collecting data from an online survey of approximately 400 patients with SAH in the United Kingdom to document how well PTSD is being picked up within clinical practice and to what degree patients are being supported for this difficulty. The findings have not yet been analyzed, but if we find that a significant number of cases are not being picked up then this research could lead to recommendations for routine use of specific screening measures for PTSD in clinical practice.[2]

If successful, the development of therapeutic approaches to reduce the PTSD in patients with SAH and their SOs, together with early identification, and the kind of tailored counseling described in Dr. Heros' editorial could then ensure that patients with SAH and their SOs will reap the full benefit of the impressive improvements in the management of SAH that have been achieved in recent years as consequences of scientific and technological advances in neurosurgery and neuroradiology.

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